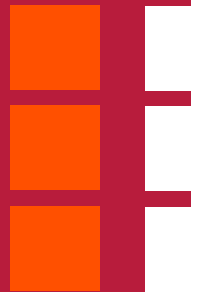


Guidelines for Including People with Disabilities in Research



National Disability Authority
2002

Contents

Acknowledgements	5
Executive Summary	6
1. Introduction	7
2. Background	9
3. Key Considerations for Inclusion	12
3.1 Planning for Inclusion	12
3.2 Access	12
3.3 Etiquette and Language	14
3.4 Disability/Equality Awareness	14
Summary	15
4. Models of Including People with Disabilities in Research	16
4.1 Participatory Research	16
4.2 Steering and Advisory Committees	20
4.3 Consultation and Planning Groups	20
4.4 Employing Researchers with Disabilities	21
4.5 Respondents in Research	22
Summary	27
References	28
Appendix 1: Guidelines for Participatory Action Research	30
Appendix 2: Useful Contacts	40
Appendix 3: Feedback Form	43

The first part of the document discusses the importance of maintaining accurate records of all transactions. It emphasizes that every entry, no matter how small, should be recorded to ensure the integrity of the financial data. This includes not only sales and purchases but also expenses and income. The document provides a detailed list of items that should be tracked, such as inventory levels, supplier payments, and customer orders. It also outlines the procedures for reconciling accounts and identifying discrepancies. The second part of the document focuses on the analysis of the recorded data. It describes various methods for interpreting the information, such as comparing current performance with historical trends and industry benchmarks. The document also discusses the implications of the data for decision-making, highlighting the need for timely and accurate reporting. Finally, the document concludes with a summary of the key findings and recommendations for future actions. It stresses the importance of continuous monitoring and adjustment to ensure the organization remains on track with its financial goals.

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The first part of the document discusses the importance of maintaining accurate records of all transactions. This is essential for ensuring the integrity of the financial statements and for providing a clear audit trail. The second part of the document outlines the various methods used to collect and analyze data, including interviews, surveys, and focus groups. The third part of the document presents the results of the study, which show that there is a significant correlation between the use of accurate records and the reliability of the financial statements. The fourth part of the document discusses the implications of these findings for practice and for future research. The fifth part of the document provides a conclusion and a list of references.

Acknowledgements

The production of these guidelines would not have been possible were it not for the contributions of certain people who were involved in the consultation process.

Special thanks is due to:

- The Kerry Network of People with Disabilities: Jacqui Browne, Cormac Daly, Gary Finlay, Mary Murphy, Mary Grantfield, Noel O'Neill, Margaret O'Shea.
- 'Pathways' Research Team: Liz Brosnan, Sean Collins, Louie Maguire, Angela, Sean Stitt, Anne, Helen Dempsey, Niamh Morrin.
- 'Making Minds Matter': Patsy Doolin, Angela McParland.
- Ewen Speed: Department of Sociology, Trinity College Dublin.

Thanks is also due to:

- Participants in the research workshops at the NDA regional consultation meetings in Galway, Dublin, Cork, Limerick, Athlone and Sligo, May-June 2002.
- Brian Dillon: Nexus Research Co-operative.
- Dr. Pauline Faughnan & Mairide Woods: Social Science Research Centre, University College Dublin.
- Dr. Margret Fine-Davis: Centre for Gender and Women's Studies, Trinity College Dublin.
- Peter Kearns: The Workhouse.
- Dr. Rob Kitchin: Department of Geography, NUI Maynooth.
- Prof. Brian Nolan & Dr. Dorothy Watson: Economic and Social Research Centre (ESRI).
- Michael Shevlin: Department of Education, Trinity College Dublin.

The position outlined in this document is that of the NDA and does not necessarily reflect the views of those who participated in the consultation process.

Executive Summary

The National Disability Authority (NDA) considers that the inclusion of people with disabilities in research on issues which affect their lives is an essential element of ensuring that disability research accurately reflects the perspectives of people with disabilities and remains focused on the issues of greatest importance to them. To promote an inclusive approach to disability research the NDA has established these guidelines, which identify some of the key considerations for inclusion and outlines models that researchers can use to include people with disabilities in their research.

Key Considerations for Inclusion:

There are some key considerations which should be applied to any inclusive approach to disability research. These are:

- Planning for Inclusion
- Making the Research Process Accessible
- Using Appropriate Language
- Being 'Disability Aware'

Models of Inclusion:

The diverse nature of research means that some ways of including people with disabilities will be more suited to some projects than others, depending on the methodology employed and on the scope of the research. Some projects may also involve different ways of including people with disabilities at different stages of the research process. Some of the models of inclusion which researchers can consider are:

- Participatory Approaches to Research
- Steering and Advisory Committees
- Consultation and Planning Groups
- Employing Researchers with Disabilities
- Including People with Disabilities as Research Respondents

1. Introduction

The National Disability Authority (NDA) is a statutory body with a key role in promoting and securing the rights of people with disabilities. The Authority seeks to achieve this by influencing public policy and legislation and by ensuring that services to people with disabilities are of the highest standards and quality.

The Strategic Plan 2001 - 2003, “*A Matter of Rights*”, outlines the current strategic priorities of the NDA. Priority 1 states that the Authority will “develop policies that promote the equal status of people with disabilities”. One of the objectives under this priority is to develop guidelines “for effectively including people with disabilities in all aspects of research that affect them.”

This aim emerged from the consultation process which the NDA conducted with people with disabilities prior to completing its Strategic Plan. It reflects the fact that people with disabilities were dissatisfied with traditional methods of disability research, which were seen as exclusionary and based on the idea of an ‘expert’ researcher doing his/her research *on* disability and *on* people with disabilities. Such exclusionary methods led to research findings which people with disabilities felt did not fully reflect their actual experiences and needs. These research guidelines identify ways in which disability research can be done *with* and *by*, rather than *on* people with disabilities.

Social model of disability

The NDA is committed to a social model of disability, which places a person’s impairment in the context of the social and environmental factors which create disabling barriers to their participation in society. This contrasts with more medical and individual concepts of disability, which equate a person’s impairment with their disability, without placing it in context. For example, employing the social model of disability would mean that a wheelchair user cannot get into a building because of the planning and design of the building or the attitudes of the owner, rather than being unable to climb steps. The NDA’s commitment to the social model is stated in the core values outlined by the Authority in its Strategic Plan, which states:

“The National Disability Authority will proactively adopt a civil and human rights perspective in the development of policy and practice for people with disabilities. Grounded in the social model of disability and the principles of equality, participation and choice put forward by the Commission on the Status of People with Disabilities, this rights-based approach will seek to:

- Ensure that the needs and rights of people with disabilities are enshrined in all aspects of Irish life;

- Promote the empowerment of people with disabilities and their participation in decisions that affect their lives;
- Underpin the promotion of an inclusive vision among all constituencies in Irish society.” (NDA, 2001: 16)

In keeping with the principles of a social model of disability, reference to ‘disability’ in this document will mean:

‘The disadvantage or restriction of activity caused by a contemporary social organisation which takes no or little account of people who have (a physical, sensory, learning, mental health or emotional impairment) and thus excludes them from participation in the mainstream of social activities’.¹

¹ Based on UPIAS (1976) *Fundamental principles of disability*, Union of Physically Impaired Against Segregation, London.

2. Background

The decision to produce guidelines for including people with disabilities in research emerged from dissatisfaction with the way traditional disability research was carried out, and the role that people with disabilities had within such research. Features associated with this traditional approach to disability research include:

- Identification with a medical/individual definition and model of disability - as opposed to a social model;
- 'Expert' or professional-led research conducted on people with disabilities, excluding them from the process and treating them only as research subjects;
- A lack of findings and outcomes which were rooted in and reflected the real experiences and needs of people with disabilities;
- An absence of any real action and follow-on from research, with a consequent lack of change in the lives or situation of people with disabilities.

Throughout the 1990s, several researchers and commentators identified the need to change the way disability research was carried out.² With a focus on a social model of disability, commentators such as Oliver and Zarb forwarded models of 'emancipatory' research as a response not only to the exclusion of people with disabilities from the research process, but as a necessary reaction to the oppression of people with disabilities in society and the systematic denial of their rights.

Emancipatory research, as first identified by Oliver (1992), was based on changing the *social relations* of research production. In other words, for emancipatory research to be possible the balance of power within the research process would have to change, and move towards a more equal relationship between the researcher and the people with disabilities who are being 'researched'. Disability research would have to be done *with* (i.e. in partnership with) people with disabilities rather than *on* them - as had been the case with traditional approaches.

Zarb later added that while changing the social relations of disability research was a necessary way of making research more inclusive of people with disabilities, a further step was necessary in order to make the research process truly 'emancipatory'. Zarb argued that if disability research was to be part of the wider process of empowerment and emancipation then it was not simply a case of addressing power and changing the social relations of the research, but also that the material relations of the process (e.g. funding, status, power) would also have to change. To

² For a summary of the main points and arguments see Abberly, Oliver, Zarb and others in 'Disability, Handicap and Society' (1992) Vol.7, No.2; and Barnes and Mercer, Oliver, Ward, Zarb and others in 'Doing Disability Research'(1997), edited by Barnes and Mercer.

achieve an empowering and emancipatory model, changing control of the resources needed to undertake research is as important as the balance of control within the research process (Zarb, 1992).

Given the complexities involved in attempting to change the material relations of research production, some researchers focused on a model which attempted to change the social relations, such as a 'participatory' approach to research. This is an approach to research which attempts to make the relationship between researcher and researched an equal partnership, while working within the existing material relations - e.g. while working within existing structures of funding, or within a system which regards academic attainment as *the* prerequisite for being able to do research.

Regardless of whether they adopted approaches which were defined as 'emancipatory' or 'participatory', many researchers faced practical difficulties when they attempted to move away from traditional exclusionary ways of doing research. For example, Campbell and Oliver (1996) undertook a piece of research which attempted to take an emancipatory approach. However, contrary to the principles of emancipatory research, Oliver later admitted that:

- The original initiative and focus for the research came from the research team;
- The researchers secured the funding themselves;
- They made all decisions in relation to the focus and direction of the research; and
- They decided who to interview and what methods would be used.

Oliver pointed out that they had neither the time, energy nor resources to "make it a wholly collective production", and that "ultimately we were in control" (Oliver, 1997). The time and resources mentioned here are among the key elements of the material relations of any research process.

In a project entitled '*Measuring Disablement in Society*', Zarb (1997) also faced obstacles to conducting emancipatory research due to the existing material relations of research. These obstacles included barriers to employing people with disabilities to work on the project, and a lack of resources required to facilitate the maximum involvement of local people with disabilities.

Kitchin (2000) looked beyond the difficulties posed when attempting to translate 'emancipatory' principles and theories into workable methodologies when he examined the views of people with disabilities who had been researched, in order to identify a model which could be applied practically. The model, called Participatory Action Research (PAR), is based on changing the social relations of research by creating an equal partnership between a researcher and people with disabilities - as a team which does the research together. This model is examined further in section 4.1.1.

The guidelines outlined in this current document aim to identify practical ways to include people with disabilities in research. They aim to influence an inclusive approach to research which reflects the priorities and concerns of people with disabilities. They were developed through an

initial examination of literature on disability research, which was followed by a process of consultation with a range of sources, including:

- Three groups of people with disabilities who had conducted their own participatory research projects;
- Researchers who have been involved in a range of different types of disability research as well other types of social and economic research;
- People with disabilities, their family members and carers who attended the research workshops during a series of regional meetings held by the NDA's Research & Standards Development Department in Galway, Dublin, Cork, Limerick, Athlone and Sligo, throughout May and June 2002.

This process has facilitated a broad view which has identified *why* disability research should be more inclusive of people with disabilities, and *how* researchers can apply different strategies and models to make their research more inclusive of the people who are most affected by the issues in question.

3. Key Considerations for Inclusion

This section outlines some of the key factors which researchers should consider to ensure that their research effectively includes people with disabilities who are representative of the target population of their projects. These factors should be considered, and used where appropriate, regardless of the model researchers use to include people with disabilities in their research. Researchers requiring clarification or more detailed information on inclusive methods for people with specific types of disability should refer to the organisations outlined in Appendix 2.

3.1 Planning for Inclusion

While the fact that a person has a disability does not automatically mean that they will require any specific assistance or support to become included in research, the best way to identify what methods and supports for inclusion may be required is to simply **ask those you wish to include**. Planning for any specific types of support or assistance for inclusion in research should be the first part of any inclusive project. Individuals with specific types of disability who are amongst the research target population, or groups representing them, should be consulted in the planning phase to identify what kind of needs should be addressed. This will enable researchers to identify and respond to the specific needs of the people they want to include in their research.

3.2 Access

Researchers planning for inclusive research need to ensure that the process is accessible³ to the people they want to include. This includes ensuring that venues, communication, information and transport are accessible where required. (More detailed information on access is available in *'Ask Me: Guidelines for Effective Consultation with People with Disabilities'* (NDA, 2002a). Researchers should also refer to Appendix 2 for details of representative organisations and organisations who provide assistance with accessible communication, transport and personal support.)

3.2.1 Accessible Venues

Researchers conducting meetings, focus groups, interviews or any other type of research which requires use of a venue, need to ensure that the venue is fully accessible to the people attending. For example, people with mobility impairments using a wheelchair will require a ramp or level access to a venue, a lift instead of stairs, sufficient room to move inside the venue, and accessible toilet facilities. Comprehensive guidelines on ensuring access to, and use of, buildings for all people with disabilities can be obtained from *'Building for Everyone - Inclusion, Access and Use'* (NDA, 2002b).

³ Broadly speaking, ensuring that something is fully accessible means that people with disabilities can enter and/or make use of a place, a good or a service with ease and without embarrassment.

3.2.2 Accessible Communication

Any research which requires communication with people with disabilities should be planned to address any specific communication difficulties which people have. This may include:

- In a meeting situation, people with hearing impairments may require sign language interpretation or a loop system;
- People with mental health difficulties may benefit from pre-meeting contact to overcome fears of being stigmatised within a gathering;
- People with learning difficulties can be included more where language used is kept simple and direct, avoiding the use of jargon or abstract ideas;
- People who are blind will require a verbal description of any information presented on overheads or slides.

In communication with people with disabilities researchers should also ensure that the language used is appropriate and acceptable in all cases (see section 3.3).

3.2.3 Accessible Information

Different types of disability research will also require the production of information for use by people with disabilities. Any form of information produced should take account of the different needs of people with different types of disability researchers need to include. Making information accessible means ensuring that any documentation used at various stages of research (such as information sheets, correspondence, questionnaires, research reports, etc.) is made available in a range of different formats suited to the needs of individuals. Effective planning for inclusion will help identify what formats will be needed for different projects. Making information accessible can include:

- Providing information on disk or email for people with visual impairments so they can access it with their assistive technology (which might also be made available). Alternatively, people with visual impairments may require information in large print, in Braille, or on audio cassette, depending on individual needs;
- Providing easy-to-read or 'Plain English' versions of information to people with learning difficulties. This format avoids jargon and uses simple, direct language to enable people with learning difficulties comprehend the information being provided.

Again, researchers should ensure that language used is appropriate and acceptable in all formats of information used.

A useful resource for making technology-based information accessible are the '*Irish National IT Accessibility Guidelines*' (NDA, 2002c), developed by the NDA and available free at www.accessIT.nda.ie. They include descriptions of high level accessibility goals and the difficulties faced by users, prioritised guidelines for different types of technology (Web, Telecoms, Public Access Terminals, and Application Software), as well as guidance on design techniques and testing methods.

3.2.4 Accessible Transport

Research which requires people with disabilities to travel, to attend meetings or otherwise, should be planned to ensure that people have access to appropriate transport. Limited availability of accessible transport may restrict some participants and researchers with disabilities from getting to and from venues. Arranging venues that are as close as possible to groups of people included in the process, making adaptations to vehicles or arranging for alternative accessible transport are some ways in which transport difficulties can be overcome.

Researchers should also note that some people with disabilities may require more **time** in carrying out various activities and may also rely on personal assistants or carers. Therefore, researchers should plan meetings at times which account for this - e.g. avoiding very early starts.

3.3 Etiquette and Language

'Ask Me' (NDA, 2002a) provides a disability etiquette checklist which outlines useful information for researchers who want to include people with disabilities in their projects. This includes what type of language is appropriate for use when writing about, describing or meeting people with disabilities. It also includes a sample list of terms which should and shouldn't be used, taken from *'Making Progress Together'* (People with Disabilities in Ireland, 2000). Representative organisations can provide further disability-specific information to researchers where required (see Appendix 2). Some key aspects include using terms such as:

- 'People with disabilities' instead of 'the handicapped';
- 'Person with a disability' instead of 'cripple', 'spastic' or 'victim';
- 'Learning disability' instead of 'mental handicap';
- 'Person with a mental health disability' instead of 'schizo' or 'mad';
- 'Person who uses a wheelchair' instead of 'wheelchair-bound';
- 'Non-disabled' or 'able bodied' instead of 'normal'.

Disability etiquette in a research context can also include directly addressing a person with a disability rather than a carer or Personal Assistant in meeting situations. This can be particularly important when, for example, including people with communication difficulties as respondents in interviews. It may be necessary to include an interpreter to facilitate communication in such a situation. However, it remains important to directly address the respondent as much as possible and not the interpreter.

3.4 Disability/Equality Awareness

It is important for researchers to ensure that they, and any of their research staff, have a sufficient level of disability awareness when undertaking disability research and including people with disabilities. Disability/Equality awareness for researchers can involve:

- Understanding what is meant by 'disability' and how people with different types of impairment are disabled;
- An understanding of the social model of disability;

- An understanding of the social, economic, political and cultural issues and concerns which affect people with disabilities;
- Acknowledgement of the rights of people with disabilities, within the broader concept of equality for all members of society;
- Use of appropriate language that is acceptable to people with disabilities;
- Awareness training.

Researchers should make sure that they have an understanding of these issues before conducting research with people with disabilities. Formal awareness training and further information on different types of disability can be obtained through organisations identified in Appendix 2.

Summary

This chapter has identified some of the key issues which are essential for researchers to consider when undertaking disability research and attempting to include people with disabilities in the process. Issues identified have been: planning for inclusion, ensuring that the research process is accessible, using appropriate language, being aware of what 'disability' means and entails, and being aware of the priorities and concerns of the target population of research projects. These should be addressed regardless of the way in which researchers plan to include people with disabilities, or the model of inclusion they apply to their research. The following chapter identifies example models of how researchers can shape their projects to include people with disabilities in the process, either as co-researchers, respondents, or in an advisory or consultative capacity.

4. Models of Including People with Disabilities in Research

The inclusion of people with disabilities in research has been identified as something which the NDA promotes because it ensures that research remains focused on the issues and concerns of greatest importance to people with disabilities. However, not all disability research is the same and different types of research projects will require different methods. Similarly, different types of disability research will be suited to different ways of including the target population of people with disabilities. Therefore, while some essential principles and procedures will apply to all types of inclusive research (such as ensuring that the research process is accessible to people with disabilities), these guidelines have identified various different models for including people with disabilities which researchers can employ in different projects, or at different stages of a project. Models which have been identified as suitable to the inclusion of people with disabilities from the target population of research include:

- (i) Participatory Research;
- (ii) Steering and Advisory Committees;
- (iii) Consultation and Planning Groups;
- (iv) Employment of Researchers with Disabilities;
- (v) Including People with Disabilities as Respondents.

4.1 Participatory Research

Participatory research is the most inclusive model of disability research that has been identified in practice during the course of this project. This is because the research done is conducted by people with disabilities who are representative of the target population of the project - i.e. the researchers are people who are, or have been, directly affected by the issues at the centre of the research question and aims. One model of participatory research which has been conducted successfully in Ireland in recent years is 'Participatory Action Research' (PAR). Another model, 'Participatory Learning and Action' (PLA), has been identified from other fields of social research as having possibilities for being adapted for disability research.

4.1.1 Participatory Action Research (PAR)

In practice, the research team is made up of research 'participants' (i.e. people with disabilities who have been affected by the central research issues) and a 'researcher'⁴ (or researchers) who acts in a consultative role. Each of these parties contributes their respective skills and expertise

⁴ 'Researcher' in this context refers to the consultant in the PAR process, and usually implies somebody who has formal research training, skills and experience.

to the research process, yet the participants are the ones who make the key decisions around the focus and direction of the research, from beginning to end. The consultant's main role is to provide any research expertise that the participants may require in addition to their own, and to provide research training to the participants where and when it is required throughout the project. Key features of PAR include the following:⁵

- The process is based on an equal partnership between the researcher and people with disabilities;
- The researcher acts as consultant rather than expert;
- People with disabilities take an active and involved role in the whole process, from inception and initial ideas through to the reporting and dissemination of findings;
- The research uses an action-led approach which explicitly aims to use the research to change the lives of people with disabilities.

PAR has been found to work very well at a local level or where a group or organisation of people with disabilities have identified a research topic of importance to them, where they initiate the research and perhaps bring in additional research expertise from a consultant when needed later on. This model can also work well from a researcher's or research institute's point of view in that they could form or identify a group of people with disabilities to act as the participants for a piece of research that they want to conduct.

The following examples provide a brief outline of how a project based on the PAR model might take shape. They may not be entirely suited to different individual projects, and may be tailored to suit the needs and requirements of each project and the research partners involved. What is important is that the PAR project retains the key elements identified above - i.e. it is based on an equal partnership between the researcher (in 'consultant' not 'expert' role) and people with disabilities who take an active and involved role in all aspects of the research, which remains action-led. Detailed guidelines and considerations on different aspects of PAR have been developed in consultation with three groups of people with disabilities who conducted such research themselves. These are outlined in Appendix 1.

- (A) If the research is initiated by a group of people with disabilities:
- (i) A disability group/organisation identifies an issue on which it needs concrete information/data (e.g. the housing conditions and needs of people with disabilities in a particular area);
 - (ii) A group of participants from the group/organisation is assembled to take part in the process;
 - (iii) They begin to plan for the research: e.g. identifying what important aspects of the research topic need to be included - formulating the research question and aims of the project - and establishing what skills and resources will be needed to complete the project;
 - (iv) Based on available and required research skills and experience, the group can proceed to undertake the research themselves or, in a situation where there is a shortfall between available and required skills, decide to bring in a skilled and experienced researcher to consult on the research areas in which the group is lacking;

⁵ Based on Rob Kitchin's 'The researched opinions on research: disabled people and disability research.', *Disability and Society*, Vol. 15, 1 (2002).

- (v) The group of participants and the consultant carry out the research in partnership, based on agreed ground rules and identified roles and responsibilities;
 - (vi) The participants remain in control of the key decisions about the focus and direction of the research, with the consultant providing assistance and perhaps identifying options for progress at different stages in the research.
- (B) If the research is initiated by a researcher or research organisation:
- (i) A researcher identifies an issue on which he/she wants to conduct a piece of research - e.g. through an identified priority of a group of people with disabilities, or through tendering for a piece of research on a disability topic;
 - (ii) Depending on the topic and/or the geographic area covered by the research, the researcher either: (1) identifies an existing group of people with disabilities who have been affected by the central research topic; or (2) forms a group of people with disabilities who are representative of the target population of the research. Either way, the researcher employs the group to participate as research partners in the project in order to gain their experience and expertise of the issue. The researcher may decide to establish more than one group, depending on geographic coverage, and feed findings from each one into regional or national outcomes;
 - (iii) The researcher facilitates the research planning, whereby the group identify what important aspects of the research topic need to be included, formulate the more specific aims of the project, and establish what skills and resources will be needed to complete the project;
 - (iv) The group of participants and the consultant carry out the research in partnership, based on agreed ground rules and identified roles and responsibilities;
 - (v) Ideally, the participants remain in control of the key decisions about the focus and direction of the research, with the consultant providing assistance and perhaps identifying options for progress at different stages in the research.

4.1.2 Participatory Learning and Action (PLA)

A model of participatory research which grew out of rural development strategies, Participatory Learning and Action (PLA), has since been adapted and used in areas of social research. The model is seen to have uses for gaining a more holistic picture of the issues at the centre of research projects and involving participants as partners in the process. In PLA, “outsiders act as facilitators for local people, who join in determining the agenda, issues, and concerns and in collecting the material, interpreting it, and acting on it.” (Kane & O’Reilly-de Brùn, 2001). This parallels the process involved in PAR, whereby ‘outside’ researchers act as consultants in order to facilitate the participatory project, in which local people or people with disabilities (i.e. the target population of the research) are the research partners. In practice, therefore, the PAR and PLA models are quite similar.

Kane & O’Reilly-de Brùn (2001) identify some of the key features involved in a PLA research process. Adapting these for disability research, these features include:

- Often the target group (people with disabilities) initiate the process;

- The target group decides what the research issues are, what it needs to know, how it will find out, and from whom - i.e. the research focus reflects the real topics of concern to people with disabilities;
- Outside researchers usually contribute special expertise about the research topic that concerns the target group, as well as experience of the PLA process;
- Where researchers are involved, their task is to share their experience of PLA, rather than to control the project. The aim is to empower the target group to carry out the process so that they do the work and 'own' the results. This means that people concerned do the research, rather than the researcher(s);
- The target group may require input from people with special expertise or control of resources;
- Once the target group has been through the PLA process, it may feel comfortable repeating it and training others without the help of outside researchers;
- Appropriate action plans, together with procedures for carrying them out and monitoring them, need to be developed to generate actual outcomes from the research findings.

Kane & O'Reilly-de Brún (2001) assert that the PLA model of research works best at a local level, or where the findings and follow-on actions can be effectively addressed and implemented without relying on policy or institutional changes on a larger scale. However, they also point out that the model may have uses on a wider scale or as part of a larger study. An example of how this might be achieved by researchers and research organisations can be seen in the model used by the National Women's Council of Ireland (NWC), as part of their national study entitled *'Women Mapping the New Millennium'*. The NWC Millennium Project aimed to ascertain women's views on priority issues. To allow for the effective communication of views from local grassroots level, the NWC adopted a PLA model of research.

"Adopting a PLA approach and method means that participants in the research process share and analyse information and knowledge, identify constraints and possibilities related to the topic in question, and, where possible and appropriate, plan positive action" (NWC, 2001).

The process involved the training of 118 participants in PLA research techniques in several different centres around the country. These women then went into the field to facilitate research groups of women which focused on issues of concern selected from a list of 'national' issues. The findings were later collated, analysed and fed into the development of strategies and action planning at both local and national level for the NWC.

The process in which the NWC engaged demonstrates how an organisation or institution can adopt a participatory approach to examining topics which are of concern to its 'grassroots'. For disability organisations or research institutions seeking to conduct large-scale research projects on disability topics, this model provides an example of how people with disabilities could be included in such a research process.

4.2 Steering and Advisory Committees

Another model of including people with disabilities in research is as members of either a research steering or advisory committee. In this capacity, people with disabilities who are appointed to either type of group will give advice, input and feedback at various stages of the research process. The level of influence which such groups have can depend on the level of input and additional expertise the researchers require, or how willing they are accept the group's input and advice so that their research benefits from the knowledge and expertise that the group has of the research topic(s).

By definition, a research 'steering committee' will have more of an influence and say over the research, whereas an 'advisory committee' will provide advice which the researcher can consider in light of their own experience and expertise, and make decisions about the research themselves. The terms of reference and power of committees should be established at the outset. Both types of committee act as a resource to provide ideas and direction in the planning stage and feedback at intervals throughout the research process, with the researcher carrying out the research tasks in between each feedback interval. The following example is an outline of how this model might look in practice:

- (a) A researcher/research organisation identifies a piece of disability research that they wish to undertake - e.g. through an identified priority of people with disabilities, or through tendering for a piece of research on a disability topic;
- (b) They establish a steering or advisory committee made up of people with disabilities representative of the research target population;
- (c) Project Planning: the researcher consults the committee to identify important issues that should be covered in the research, then draws up a research plan;
- (d) Feedback on plan: the committee assesses the research plan and provides feedback to the researcher;
- (e) The researcher revises the plan based on feedback received;
- (f) Task 1: the researcher undertakes the first research task;
- (g) Feedback 1: the committee assesses task 1 and provides feedback to the researcher;
- (h) Task 2: the researcher undertakes the second research task;
- (i) Feedback 2: the committee assesses task 2 and provides feedback to the researcher.

This process is continued throughout each stage of the research project, right up to the final report, outcomes and any follow-on actions. The researcher and committee may decide that input and feedback from the committee is only necessary in the planning phase and thereafter at stages where a significant piece of the research has been completed by the researcher.

4.3 Consultation and Planning Groups

Another model of ensuring that people with disabilities, and their views and concerns, are included in research is through the use of consultation and planning groups. Prior to starting a research project, a researcher identifies the key issues of importance and concern to the target population through a consultation or planning phase.

This can be approached with a clean slate, whereby the researcher asks the group to identify a key topic of concern on which to focus the research. It can also be used in a situation where the researcher brings ideas for their research to the group to establish their relevance to the target population and to receive further ideas on the specific direction and focus for the research. Either approach will give the researcher an insight into what topics are relevant to the target population and where the focus for the research should be.

This approach can also be used effectively for organisations who are planning a strategic research programme over a period of time. It will help the organisation to identify projects which are of greatest relevance and concern to people with disabilities.

4.4 Employing Researchers with Disabilities

The consultation process involved in establishing these guidelines has also identified the value and use of researchers and research organisations employing other researchers with disabilities to work on their projects. The main benefit of this to research was highlighted where researchers with disabilities similar to those of the target population were employed to undertake fieldwork which involved meeting respondents. In an element of research in which building rapport with respondents is very important, some respondents may feel more empathy and understanding from an interviewer with a similar type of impairment as they have themselves. It has been found that respondents can be more open and frank with researchers they feel can empathise with their situation (Alderson, 1995; Ward, 1997).

Employing researchers with disabilities similar to those of the research target population can also be of value in terms of utilising disabled people's experience and expertise to inform the content of the research, and in terms of directly challenging social and economic exclusion. It can also be a way of ensuring that researchers employed can demonstrate an awareness of some of the fundamental research issues around disabling barriers, which should be allied to practical experience of research methods - although this might be a secondary requirement as methods can more easily be taught (Zarb, 1997).

The employment of researchers with disabilities for a project should be thoroughly guided by the considerations on accessibility identified in section 3.2 - as should any model of inclusive research. Some of the more fundamental considerations which may arise in this regard are:

- Travel and transport - problems may arise if disabled researchers with mobility difficulties have trouble accessing appropriate transport in order to conduct fieldwork or travelling to meetings, etc. Researchers/organisations employing such researchers should ensure that appropriate accessible transport is available or made available;
- Researchers/organisations should consider providing equipment suited to the more effective employment of disabled researchers, such as assistive technology, adapted workstations, voice-controlled computer software, or electric wheelchairs;
- Some disabled researchers may benefit from flexible working arrangements, such as working from home or working part-time;
- Providing, or meeting the cost of, personal assistants for researchers with disabilities will be crucial to those who rely on this type of support.

Appropriate research planning should be used at the outset of a project to identify any needs or specific supports which a disabled researcher might have in order to perform his/her duties.

4.5 Respondents in Research

Many researchers' experience of including members of the target population in their research consists of inclusion as respondents. This model of inclusion is also important for disability research and the inclusion of people with disabilities. It also has added significance for disability research due to the fact that some researchers might assume that certain people with disabilities are unable to contribute to research as respondents on account of an impairment.

It is incumbent on researchers to make every effort to include people with disabilities as respondents in their research where that research requires ascertaining the views of people with disabilities. Furthermore, researchers should plan to include people with disabilities as **direct** respondents whenever possible. Researchers may encounter difficulties in this regard where the respondents are people with communication or learning difficulties. However, in these circumstances there are measures that researchers can take to maximise this type of inclusion for all people with disabilities, including people with communication difficulties or learning disabilities.

Another consideration for including people with disabilities as respondents in research is an adherence to ethical research standards, such as ensuring that proper informed consent is obtained from the individual before taking part. Again, these issues are not exclusive to the disability field of social research and apply to many other groups of respondents. However, there are some aspects that are specific to disability research which need to be considered. The following are the key considerations for including people with disabilities as respondents in research.

4.5.1 Access and Awareness

While issues of access and awareness apply to any of the models included here, and have been covered in more detail in section 3.2, it is worth pointing out their significance again in relation to including people with disabilities as respondents in research. Ensuring that the process involved is fully accessible in terms of information, communication, venues, transport and any other important aspects, should be an essential first consideration for researchers. Proper research planning will identify any important issues which are likely to arise - especially when people with disabilities have also been included in the planning, as outlined in the other models above.

4.5.2 Disability Research Ethics

While no specific codes of ethics for disability research were found, consultation and review of existing literature has identified some key ethical issues which apply to including people with disabilities as respondents in research. Some of these issues exist in the formal codes of ethics on research participants from sociological and psychological associations. Others have been derived through the work of researchers such as Ward (1997), Beresford (1997), and through consultation with a range of people involved in researching disability issues.

The American Sociological Association's (ASA) Code of Ethics states that it has as its primary

goal “the welfare and protection of the individuals and groups with whom sociologists work.” The Ethical Guidelines of the Sociological Association of Ireland (SAI) states that its members “have a responsibility to ensure that the welfare of research participants is not adversely affected by their research activities.” The Psychological Association of Ireland’s (PSI) Code of Professional Ethics, which cover members’ research activities, states that its members should have regard for participants’ values, refuse to engage in practice which infringes on their rights, and not allow their service to be diminished by factors such as disability.

Ward (1997) notes that, in relation to ethical research, the challenge for researchers aiming to include people with disabilities as respondents is to develop strategies and safeguards to facilitate appropriate participation. Beresford (1997) identifies *informed consent* and *dealing with disclosure* as the two key issues in relation to the practical aspects of ensuring that a research project involving people with disabilities adequately addresses ethical demands. These issues are also identified in the codes of the ASA, SAI and PSI. Other key issues identified in consultation, research and existing ethical codes are acknowledging the *right of refusal to take part* in research and establishing appropriate *support structures* to deal with any effects which involvement in research could have on respondents - which can be particularly important when sensitive issues are raised in an interview.

These four key issues can all be identified as integral parts of any ethical approach to disability research and the involvement of people with disabilities as respondents. Combined, they should contribute to principles and strategies which are essentially designed to protect the rights, safety, dignity and wellbeing of people with disabilities who participate in research in such a capacity.

Informed Consent:

Beresford (1997) notes that there are three elements to gaining the informed consent of respondents:

- (a) It is based on knowledge - gained by means of information presented in understandable terms;
- (b) It is voluntary;
- (c) The individual has the capacity or competence to give consent.

Gaining the informed consent of a prospective respondent in research requires that researchers must provide appropriate information regarding the nature and aims of the project and of the person’s involvement. Providing such information for people with certain types disabilities can raise challenges for researchers. Researchers must ensure that the information is provided in formats which are understandable and accessible for the target group. This might involve, for example, providing information in Braille, large print, audio tape, or on electronic disk for people with visual impairments.

A further challenge is presented where researchers want to include people with learning disabilities as respondents. The use of simple and direct language, avoiding jargon or abstract ideas, is one measure that researchers can use to provide appropriate information to people with a reduced capacity to understand and reason. This may involve providing information sheets in ‘plain English’ and using pictures and photographs to add meaning to the words in order to make the information accessible and understandable to a person with a learning disability.

Some people with a learning disability may require the involvement of a family member, carer, advocate or other trusted individual in deciding whether or not to take part in research. However, even in this situation, every effort should be made by researchers to supply appropriate information to the actual respondent, while also fully informing the other person.

As in other aspects of disability research, initial planning will help the researcher to identify what possible needs their target group has in relation to formats and means of receiving and understanding any information provided, and whether or not the involvement of a third party will be required to assist the decision making process.

Following the provision of appropriate information, it is critical that decisions to provide consent to participate as a respondent are made freely and without coercion. Ensuring that consent is given on a purely voluntary basis can be more complex for respondents with certain types of disabilities. For example, people with mental health difficulties involuntarily held in institutions may be more vulnerable to coercion or undue influence due to the unequal power relationship between doctors and patients. Dinerstein et al (1999) notes that “institutional residents may be reluctant to participate or withdraw from a study because they fear angering or disappointing those who treat them.” Freedman (2001) recommends that research involving respondents with this type of disability should be recruited from among non-institutionalised individuals wherever possible.

Freedman (2001) also suggests that people with learning disabilities may also be vulnerable to non-voluntary consent due to “their general lack of experience with decision-making, reliance upon family and staff, desire to please others, and potential susceptibility to undue influence or coercion from others (e.g. caregivers, therapists, researchers).” Dubler (1987) stated that the more controlling and confining the setting, the more individual ability should be required by researchers to avoid duress and coercion in obtaining informed consent.

Right of Refusal to Participate:

A consequence of seeking informed consent on a voluntary basis is that prospective respondents will hold the right to refuse to participate in a piece of research, without any fear of negative impact on themselves. Again, it is the researcher’s responsibility to ensure that people with disabilities are made fully aware of this (through appropriate information) and are free to exercise this right. People with learning difficulties in particular should be made aware of this, and reminded throughout that they can end an interview if they wish, change their mind at any stage, or refuse to answer particular questions with impunity.

Disclosures:

It is possible that respondents with disabilities may disclose some information which suggests that they are at risk in some way. For example, it could be revealed that they are being abused or mistreated in some way, or that they are engaging in certain behaviour that threatens their welfare, such as drug abuse. Beresford (1997) recommends that researchers should consider and plan for how they might deal with a disclosure which they find disturbing and feel should be referred to an expert of some sort. “Where a researcher anticipates disclosures, the most appropriate course of action may be to state in the consent information that certain behaviours will be discussed with, or referred to, a responsible (person) so that the (respondent) can be helped.” This is seen to have particular relevance to children or respondents with reduced intellectual capacity.

Support:

As indicated, where disclosures are made which suggest that the respondent is somehow at risk, researchers should plan as to how they might deal with them - such as referral to a trusted friend, advocate or professional. The ASA's Code of Ethics states that researchers should "take steps to implement protections for the rights and welfare of research participants", and that in planning and implementation they should "consult those with expertise concerning any special population under investigation or likely to be affected."

Researchers should also be aware of the possible need for the provision of support to respondents where the subject matter discussed is potentially upsetting to them. This may be especially relevant where sensitive issues are being covered, and for people with mental health difficulties who are discussing traumatic or distressing incidents or issues which have affected them. Researchers should identify potentially distressing topics in research planning with people who have been affected by such issues, and establish and offer support to affected respondents involved in the research. This may include advocacy, peer support or counselling.

4.5.3 Some Alternative Approaches

Apart from ensuring that all aspects of the research process are accessible to prospective respondents, researchers may need to use alternative methods for collecting information from respondents with certain types of disabilities. This is especially relevant to respondents with communication difficulties or people with learning disabilities, and will require identifying the most appropriate methods for eliciting responses based on the specific needs of the target population.

Rapport, Setting and Time:

The involvement of some respondents with disabilities may benefit from a careful and lengthier approach to building rapport between researcher and respondent. People with mental health difficulties may, for example, benefit from an initial informal meeting prior to a more formal and structured interview situation or focus group. This can help to allay any fears of stigmatisation which such respondents might have, can help put the respondent more at ease with the researcher, and thus make for a more open response later. People with learning disabilities may also benefit from a prolonged period of building rapport with a researcher (Beresford, 1997). In addition, using a familiar setting or one in which the respondent feels comfortable, as well as times suitable to the respondent, can be important factors in facilitating a more relaxed and open interview.

Interpreter/Communicator:

For respondents who have difficulties communicating through conventional spoken or printed means, it may be beneficial to make available the involvement of a third party with whom the respondent is familiar. This third party may be someone who is familiar with the respondent's form of communication and can act as an interpreter between researcher and respondent. Ward (1997) warns, however, that the involvement of a third party who plays a specific role in the respondent's life (such as a parent or professional) can have a strong affect on how a respondent answers particular questions. This may be especially true in a situation where the research effects or is connected with the third party. It is suggested that the respondent is given a choice of person to act as communicator rather than having the decision made for them.

Type of Question:

Beresford (1997) notes that “people with learning difficulties often have difficulty answering questions which relate to time or frequency. In addition, their reasoning abilities may be limited. For example, although they have a definite preference, they may not be able to explain why they are happier in one environment compared to another.” Questions to people with learning disabilities need to be specific and concrete, rather than complex or abstract - the latter may need to be broken down into more specific items. Observational work prior to an interview, or during the time spent building up rapport, can help researchers to gauge the level at which to pitch questions. Interviewers should rephrase questions where they are not understood in the first place.

Use of Visuals:

In addition to using simpler language for respondents with learning disabilities, communication of ideas may be enhanced through the use of visual aids, such as pictures, photographs, slides, and video clips. These can help the researcher to convey his/her ideas. They can also help to increase responsiveness among people with learning and/or communication difficulties and reduce the demands made on verbal abilities. Beresford (1997) cites the example of the ‘smiley face scale’, which has been used by researchers to ascertain individuals’ feelings about particular issues. Symbol boards are used by some people who have communication difficulties. While their usefulness is limited by the vocabulary or symbols which are included, researchers could develop their own or adapt existing boards to include the words or vocabulary pertinent to the research issue.

Biases:

Researchers need to be aware of potential response biases in interviews with people with learning difficulties. These can include a disposition to respond either ‘yes’ (‘acquiescence’) or ‘no’ (‘nay-saying’) regardless of the question, or the tendency to always choose the last in a series when presented with a number of possible answers (‘recency’). Heal & Siegelman (1995) and Rodgers (1999) outline a number of techniques which can be employed to minimise these biases. For example, Heal & Siegelman note that the most common approach used to study acquiescence is item-reversal. Under this procedure an item is administered in two formats, the content being precisely reversed from one to the other; self-contradictions in which the respondent agrees with both statements are a clear indication of acquiescence.

Heal & Siegelman also note that research on the acquiescence bias suggests that it can be reduced in respondents with learning difficulties by replacing the usual ‘yes/no’ question format with an ‘either/or’ format. It was also found that enhancing the ‘either/or’ choices with accompanying picture representations of each choice is beneficial to increasing responses by respondents with learning difficulties and in reducing their tendency to choose the latter of two either/or choices.

Summary

The models and approaches to including people with disabilities in research in this chapter have been identified through consultation with a range of researchers, disability groups and individuals with disabilities. They are intended as practical ways in which anyone intending to conduct disability research can include people from the target population in their projects, depending on the type of research. In doing so, the NDA wishes to promote more inclusive disability research which is reflective of the concerns and priorities of people with disabilities.

The suggestions included are intended to give researchers undertaking disability research an indication of some of the key issues involved, and some options with regard to inclusive models and strategies. Because they attempt to address disability research as a whole, and all types of disability, a certain degree of generality has been required. Researchers may find that they require more specific information before undertaking disability related projects, particularly in relation to the specific issues associated with different types of disability and the different ways people are affected by disability. Further planned work by the NDA in this area will, for example, focus on some of the specific issues involved in doing research with children with disabilities, with a view to developing guidelines for good practice. In circumstances where further information of this type is required, researchers should use the resources of existing groups and organisations with specialist expertise in specified areas, such as those identified in Appendix 2.

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Appendix 1: Guidelines for Participatory Action Research

These guidelines were developed in consultation with three groups of people with disabilities who had conducted their own research projects. All three groups undertook their research from a point of having very little research experience or training - although this varied between individual members within each group. Their starting point was that they came together as groups of individuals with disabilities and decided (via different routes) that their long-term objectives would be more achievable with the support of quality research findings.

At certain points all three groups decided to bring in an experienced researcher to provide the additional research skills, training and support that they lacked as a group and needed to complete their projects. It is important to note however, that in doing this each group still wanted to maintain control of their research project (particularly when making decisions about the nature, focus and direction of the research), and used the experienced researcher/consultant as somebody who could provide additional guidance and help around some of the specific elements of the research when required.

These groups largely worked around the PAR model outlined in section 4.1.1. From the groups' experiences it was possible to document their progress through the participatory research process and to identify the main considerations that should be kept in mind when doing this type of research.

Note

The Kerry Network of People with Disabilities, which was one of the groups consulted in establishing these guidelines, had previously documented their experience of the research process in a CD-ROM entitled "From Visualising Inclusion to Building Inclusion - Sharing the Process" (Kerry Network, 2001). The documentation of their research process was a valuable resource in identifying many of the points contained in these guidelines, and their work provided the basis on which to build. Some of the points herein have been taken from their CD-ROM - where this occurs it will be indicated by (KN).

A. Participatory Principles

01. The participatory process should be based on an equal and interdependent partnership between participants and consultant⁶.
02. Participants should be centrally involved at all stages of the research process (from research design, to reporting, dissemination and following-through on recommendations) - particularly in decision-making about the nature, focus and direction of the research.
03. Learning should be designed around a two way process (KN). In addition to other skills and knowledge that they bring to the process, participants will have expertise in a range of disability issues and the consultant will have research expertise. Everyone involved in the process should be open to learning from other group members.

⁶ While the term 'consultant' is used here to describe the key role of the researcher in the participatory process, some researchers may prefer and identify with other descriptions – such as 'facilitator'.

04. Those involved in producing disability research, and those for whom the outcomes and findings of research is of interest and use, need to value all forms of knowledge which can be brought to a participatory research process. This means that in addition to the value placed on higher education or research skills, value should also be attributed to the knowledge and expertise gained by participants with disabilities from their life experiences.
05. Within the group (including participants and consultant) it is vital that there is:
 - Mutual respect
 - An acknowledgement of diversity and different needs
 - Trust
 - A sense of humour (KN)
06. Flexibility is an essential aspect of participatory research, particularly in relation to time. This is because training, support, capacity building and empowerment are important elements of the process - especially in a situation where participants may be new to research.

B. Planning

The planning stage of the participatory action research process is perhaps the most important, as it will provide the basis for the research and dictate how the rest of the process will develop. The following are some of the key factors of the planning stage.

07. Discussing and documenting participants' personal experiences of both disability and research can help to:
 - Identify priority research topics - for example, a group of mental health service users could map out the pathways they took through mental health services and highlight any common points to include in a survey on service users' experience of mental health services.
 - Identify considerations for conducting the research - for example, it may be necessary to make allowance for additional time or financial resources, or for providing information in alternative formats such as sign interpretation. This can apply to resources needed for the inclusion of research participants with a disability and to interviewees or respondents. Provision for any additional resources required for the full involvement of people with disabilities at all stages of a participatory research process should be seen as a standard consideration in research planning, rather than an 'unforeseen' eventuality which acts as a drain on project resources.
 - Establish a sense of trust and common purpose - the initial stages of a participatory project will also be an important time in establishing trust and good bonds within the group.
08. The research team should conduct an audit of available and required skills at the beginning of the process, with subsequent training planned around identified gaps - including the need to bring in an experienced research consultant where needed. If a group is unsure about what research skills may be needed at the different stages of the research, then a consultant could be brought in to help identify what is required.

09. It could be invaluable for groups of people with disabilities who are new to research to seek out other groups who have gone through a similar process to that which they are about to embark on. Not only will the experienced group be able to identify potential barriers and give guidance, but having been through the process of research themselves, they may also be able to act as consultant if and when the group needs one.

C. Roles and Relationships

Role Expectations

10. It is vital that all members of the research team (participants and consultant) have a clear understanding of their respective roles within the process, and that these roles are clearly defined.

The Participants' Role

11. Participants should make the crucial decisions and control the research agenda. They should look to the consultant when necessary due to a lack of research experience, skills or training.
12. The participants' role may change as the research progresses and skills are acquired. They may find that they have less need to rely on input from the consultant at certain stages.
13. Participants may find it useful to nominate a member who will drive or facilitate the research process - especially at stages when a consultant has not been appointed, or where consultant involvement is infrequent. A facilitator will generally be a leader amongst the participants on the project, and may take responsibility for chairing meetings and assigning tasks to others. This facilitation role may change between participants at different stages of the process, depending on the time, commitment or energy of individual participants at each stage.

The Consultant's Role

14. The main role of the consultant is to provide the research expertise to complement the participants' own expertise. They should provide research skills, guidance and training to participants where necessary.
15. Consultants may find a large amount of involvement is necessary at certain stages of the process, particularly the start. However, increased involvement in terms of time and effort committed to the process does not necessarily change the nature of that involvement or the consultant's role. At these stages consultants can train, inform and advise, yet still leave the critical decision-making up to the participants.
16. The consultant should be patient in their approach, encouraging constant feedback by the group and allowing the research to proceed at the participants' pace. (KN)
17. Groups of people with disabilities should be careful to choose a consultant who not only has the necessary research skills, but who shares similar values and principles, and who will practice this in his/her approach to the participatory research process. Equally, consultants and research organisations undertaking participatory research should commit fully to the principles of the process.

18. Participants may feel uncomfortable with the traditional image of a research consultant, and may equate this with a traditional (exclusionary) 'expert' approach to research. A relaxed and informal approach may encourage participants to settle into the process, increasing the level of participation. Factors within this can include the language used by the consultant (informal, simple, no jargon), and even a more informal/casual dress code.
19. It may be beneficial (although not essential) for groups to involve a locally based consultant in the research team. This may open up the use of more local resources, and help to establish contacts with different agencies and actors which may become interested parties or stakeholders in the research. Research organisations/institutions conducting a project over different regions of the country may find take advantage of this by using the research resources available in each local region.
20. A consultant with a disability may be the ideal choice to work with participants, since they can combine the necessary research skills with the perspective of a person with a disability - i.e. with an understanding of the issues of importance and concern to other people with disabilities.
21. Consultants should have a high level of disability awareness, and undertake awareness training if necessary, especially where the consultant is not a person with a disability.

Administrator Role

22. Depending on the size of the research project, groups may find it very helpful to assign the role of project administration to one or more dedicated people.
23. If involving somebody in a dedicated administration role, it is best to involve them in the process from the very beginning. Otherwise they may not get a proper sense of the process, or understand fully what is required. (KN)

Shadow Roles

24. Groups may find it useful to adopt the practice of shadowing each given role within the research process. This process means that each person who has responsibility for a given task would have an understudy who would step in to take over that role if the first participant had to drop out of the project or was unavailable for a period of time.

Housekeeping

25. In addition to involving a dedicated administrator in a project, it is useful for groups to establish ground rules and procedures to ensure easier management of files, paper work, reference materials and any other documentation relevant to the research project.

Relationships

Perhaps the single most important element in defining the success or otherwise of a participatory action research project is the strength of the relationships that exist between research partners, and the interplay between the different roles and relationships within the group. Some of the important elements of this include the following.

26. It is very important to give ample time at the start of a participatory action research process to allow the group to bond and develop the essential element of mutual trust, especially when embarking on a long process, where difficult issues may arise.

27. Sharing experiences at the start of a participatory process, and finding a common sense of purpose will act as a great unifier, as well as a driver and motivator.
28. It is important to focus on the issues rather than personalities. Where people have personal issues that are related to the issues under research, the group should try to look for shared experiences and then work them into the issues covered in the research.
29. Group support can make the difference between a project working and not working. Conflict will tend to be more easily resolved when the group have come together and are unified and cohesive. Strong relationships will also allow people to constructively and productively challenge each other.
30. Groups may find it useful to have a structured support group to run in parallel with the research team. Research teams involving mental health service users in particular have found this a useful form of support.
31. While a professional approach is necessary, the research process should also remain as informal as possible. Flexibility is an important element of this. Groups have found that frequent breaks during long meetings can help, as well as allowing a degree of latitude with agendas.
32. Developing the social aspect of a research team can build real trust and cohesion within a group. This can range from taking breaks during meetings for informal discussion, to arranging social outings - perhaps as part of celebrating milestones or particular achievements in the research process.

Involvement and Division of Labour

33. It is important to discuss and acknowledge people's different abilities to carry out different research tasks, and to account for the possibility of needing technical back-up for certain tasks. In some instances it may be necessary to create some 'division of labour', whereby other research partners undertake some of the more technical tasks. The position of any participant should not be undermined as long as they can take part in other aspects of the research and remain involved in the critical decisions. (KN)

D. Voluntarism

34. There may be situations where participants will work on research projects on a voluntary basis. This will necessitate the drawing up of certain rules to protect their involvement.
35. Contracts should be drawn up to acknowledge voluntarism where this is taking place, including adequate procedures to ensure that out of pocket expenses (such as travel and subsistence) are fully reimbursed for volunteer participants. (KN)
36. There should be respect for the fact that volunteer participants may not be able to commit the same level of time, resources or energy to the process as paid participants. This should be taken into consideration when assigning roles, tasks and responsibilities. Otherwise volunteer participants may be at risk of burnout and eventually drop out of the process. (KN)
37. Groups should ensure they respect the effort of volunteer participants and to look after their needs. Small considerations can make a huge difference - such as providing a proper lunch to voluntary participants engaged in a full day session, and respecting the fact that they may have been up very early in the morning to travel long distances to participate in the research process. (KN)

E. Rules of Participatory Engagement

38. The rules for the entire process should be negotiated as a group and drawn up as agreed and signed (KN). This may include:
- Ground rules for meetings;
 - Confidentiality;
 - Timekeeping;
 - Participation;
 - Respect for others;
 - A sense of fun;
 - Group agreement and consent.
39. Healthy group dynamics will only develop where it is based on openness, honesty and respect. (KN)
40. Flexibility is important around planning, to avoid any person dictating terms, dates or times, etc. As far as possible, decisions on all aspects of the research should be underpinned by discussion with all group members.
41. Groups may find it useful to draw up agreed rules or guidelines for resolving conflict.

F. Outcomes, Objectives and Linking Research to Action

One of the specific aims of participatory action research is that the research takes an action-led approach that explicitly aims to change the lives of people with disabilities. As such it is important for participants and consultants to be constantly aware of the need to link their research to real actions.

42. It is important for the group to consistently ask the question: “Why are we doing this?” This can help participants maintain focus on the overall objectives, even at points where the process can get bogged down in detailed methodology. (KN)
43. Participants who may not have any previous research experience should be asked to visualise what future change will be affected by the research that they are engaged in. This can help participants gain a sense of ownership over the research process and develop an understanding of the rationale for each step in the methodology. (KN)
44. At the start of the research process, participants should identify what actions will be necessary given certain findings coming from the research. Participants should link with the relevant actors and agencies from the start in order to begin the process of negotiating these actions and follow-through measures from the research findings. (KN)

G. Elements of the Process

Core Elements

45. It may help groups to structure a timeframe by implementing deadlines around each part of the research process. Participants can get a better idea of what needs to be done within specific timeframes (from week to week, month to month, or between each group meeting) and a motivating sense of achievement when each part is complete.

46. An important element in the research process is the milestone achievement system, whereby the group would mark and celebrate significant milestones and achievements in the research process - for example, establishing the research question after initial planning, completing a first draft of a questionnaire, completing interviews, or anything that the group decide on. This could be an important factor in maintaining group morale and enthusiasm during a long research process.
47. A system of internal or self-evaluation should be built into the research process. Lessons learned through this would help to inform future research. All people who have been involved in a project should individually and/or collectively assess their experience of the research, considering questions such as:
 - What were the positive aspects of the process, which facilitated your involvement?
 - What were the negative aspects of the process, which hindered your involvement?
 - Did the research meet your expectations? Why? How?
 - Did the research achieve its objectives? Why? How?
 - What elements of the research process would you repeat and what ones would you change if starting again, or for future research projects? (KN)

In addition to the above elements of participatory research, other elements have been identified during the consultation for these guidelines. While they may not apply to every participatory research project, those which involve questionnaires and/or interviewing should consider the following points.

Questionnaire Design

48. Participants who don't have previous experience in this area should be made aware of the possibilities of what can be achieved through the questionnaire, in order to reduce unreasonably high expectations or assumptions that everything can go into the questionnaire. (KN)
49. Training for questionnaire design should focus on explaining the terms, demystifying the jargon and increasing the skills base of the group. (KN)
50. Sufficient time should be spent to ensure that the group is completely satisfied that all issues are covered in a user-friendly manner, with simple language and a clear, straightforward style. (KN)
51. Groups should ensure that they take time to put sufficient effort into a pilot questionnaire, as substantial changes can often result from a good pilot survey. The pilot will also introduce participants to interviewing and the analysis of data.
52. Where groups are conducting a survey in their local area it might be useful to raise awareness of the project early on. This way it will already be in the public consciousness when the group are seeking out interviewees and respondents. Raising awareness can also raise the awareness of potential funding agencies in the area.
53. While sampling protocols need to be maintained to accurately reflect the target population, participants should also ensure that they retain a degree of control over the selection criteria for identifying a given sample, ensuring they reach the people/target group who they feel are most important to the research topic.

Interviewing & Respondents

54. Interviewees with a disability are likely to be more open when answering questions that are put to them from an interviewer who also has a disability because they feel that there is a shared sense of understanding.
55. When interviewing people who may be representing or speaking on behalf of the interviewee (e.g. carers or parents) it is important to remember that they are not the actual focus. A letter sent out in advance could draw formal reference to this fact, highlighting the fact that the focus for discussion will be the individual with the disability. (KN)
56. Respondents should be made aware of the purpose of the interview and questionnaire in advance and be given the opportunity to ask questions. An outline of the issues that will be covered in the course of the interview could be sent out to allow respondents to prepare themselves in advance of the meeting. (KN)
57. Participants should be very familiar with a questionnaire before taking it out into the field, with appropriate notes made in advance where required. (KN)
58. An ongoing review of each group member's ability to cope with the interview process should be carried out in order to examine what needs the research team members may have and what kind of support is required. Plenty of time should be allowed for participants to reflect on the interviewing process through sharing their experiences with other group members. De-briefing feedback sessions for those involved could be built into the process to examine and address any arising issues.
59. Ongoing support and back up for interviewers should be provided, either internally within the group or externally if it is felt that further expertise is required.
60. Some groups may find it useful to organise individual interviews in blocks, so that some or all of the team can be at the same venue conducting their separate interviews. This will ensure that support will be close to hand if it is required.
61. Consideration should be made of any special needs that respondents may have when sending out correspondence or a questionnaire in advance. It is likely that a range of different accessible formats will be needed, especially where the research is on a cross-disability theme.
62. A degree of flexibility is important in organising interviews with respondents, to ensure that arrangements are as convenient as possible for them. Ensure that everything is done to make the interviewee feel as comfortable as possible - including the interview venue, or catering for needs such as tea/coffee or cigarette breaks.

H. Important Considerations for People new to Research

63. Research projects need to be very carefully planned, especially where the approach is a participative one. Time taken at the planning stage can save time spent on problems later on in the process. (KN)
64. Where there is little or no experience of research, there may be an amount of uncertainty about the right approach. To avoid basing decisions on opinion rather than fact, groups may consider bringing in an external consultant with the relevant research experience. (KN)

65. Involving an interested and informed consultant from outside the group may also work to dissuade potential agendas from developing and to encourage skills of listening within the group, while acknowledging the individuality of group members. (KN)
66. Participants new to research should be aware of the limitations of research, and be realistic with regard to the extent to which research can make a difference. Sometimes one of the main findings of a research project can be that further research is necessary into a particular issue. In this way a particular research project can sometimes be a building block rather than something that can affect major change in itself.
67. Participants new to research should note that while the participatory approach to disability research breaks away from a traditional research approach in many ways, some standard rules of traditional research remain valid to the participatory approach. This is especially relevant in relation to methodology used around designing surveys, sampling, interviewing, data analysis, etc.

I. Potential Barriers to Participatory Action Research

68. While participants may be happy with the concept of participatory research and want to feed into the research, not just as subjects but also as active participants, there is a danger that limitations of time and resources, and a lack of belief in their own abilities to do the research, may hinder participation. It is important to ensure that all types and levels of input are valued, and that participants' contributions are validated and recognised.
69. There can be pressure to secure and maintain sufficient funding for the research project. Funding pressure can be alleviated by getting local groups to become involved from the start and to buy into the process as stakeholders.
70. Research funders may have certain expectations about getting something out of the research that they are funding. When these expectations are based on traditional approaches to research, and do not fully appreciate the participatory approach, then the research project and the partners involved may come under pressure to produce results quicker than full inclusion in all elements of the process will allow.
71. A project involving participants from different groups or areas, or which may be cross-disability in focus, may suffer from different forces in the group going in different directions. This danger can be reduced by taking sufficient time to build group relationships in the beginning, and by planning the research so that every partner has a clear vision of what the focus and direction will be.
72. A lack of cohesion within a group can lead to conflict over different issues in the research process, affecting the level of participation, number of participants remaining in the group, and ultimately the progress of the research.
73. Insufficient training for participants where needed can hinder progress in the research. Identifying skills gaps and needs of participants early in the research process could help to avoid this.
74. Confusion over roles within the research process can lead to a lack of progress. This is particularly relevant when identifying and clarifying the respective roles, tasks and responsibilities of the participants and the consultant.

75. Where the principles of participatory action research are not understood, and where roles are not clearly defined, there is a danger that the views and input of the consultant can become stronger than necessary around decision-making, to the detriment of input from participants.
76. Even the most cohesive and focused groups involved in a participatory research project can encounter a certain amount of frustration with the progress of the research. This is particularly true when the process, or certain parts of it (such as designing a questionnaire), drags on longer than anticipated and it feels like little progress is being made.
77. Difficulties in doing the research are more likely to arise where the involvement and input of people with disabilities has not been optimised from the very beginning of a research project.

Appendix 2: Useful Contacts

This section contains details of organisations which researchers can contact for further information on specific disability and research issues, or for assistance with accessible communications, transport and personal support for people with disabilities.

Arbour Hill Prison Braille Unit

Service which translates documentation into Braille format.

Arbour Hill, Dublin 7

Tel: 01 671 9333 Fax: 01 679 9518

Bus Eireann - Disability Consultative Committee

Tel: 01 830 2222 Fax: 01 703 3421

Web: www.buseireann.ie

Centre for Independent Living (CIL)

Campaigns for and promotes independent living for people with disabilities in order to attain inclusion.

Carmichael House, North Brunswick Street, Dublin 7

Tel: 01 873 0455/873 0986 Fax: 01 873 0998

Email: cildub@iol.ie Web: www.dublincil.org

Disability Federation of Ireland

National support mechanism for voluntary organisations covering all areas of disability and disabling conditions. Provides information, training and support, organisation and management development, research and policy development, advocacy and representation, and networking.

2 Sandyford Office Park, Blackthorn Avenue, Dublin 18

Tel: 01 295 9344/5 Fax: 01 295 9346

Email: info@disability-federation.ie Web: www.disability-federation.ie

Dublin Bus

59 Upper O'Connell St., Dublin 1

Tel: 01 872 0000

Web: www.dublinbus.ie/about_us/accessibility.asp

Forum of People with Disabilities

Organisation of people with disabilities, promoting choice, participation and full consultation.

Flat 2, 1st Floor, 21 Hill Street, Dublin 1

Tel: 01 878 6077 Fax: 01 878 6170

Email: inforum@indigo.ie Web: www.inforum.ie

Iarnrod Eireann (Irish Rail) - Access & Liaison Officer

Tel: 01 703 2634 Fax: 01 703 2515

Email: melanie.mcdonagh@irishrail.ie Web: www.iarnrodeireann.ie

Irish Deaf Society - The National Association of the Deaf

The national representative organisation of deaf people which advocates for local development, provides information on deafness, and specialises in technology development for deaf people.

30 Blessington Street, Dublin 7

Minicom: 01 860 1910 Tel: 01 860 1878 Fax: 01 860 1960

Email: ids@indigo.ie Web: www.irishdeafsociety.org

Irish Sign Link

National agency for the provision of Irish Sign Language interpreters.

25 Clyde Road, Ballsbridge, Dublin 4

Tel/Minicom: 01 608 0437 Fax: 01 668 5029

Email: signlink@indigo.ie

Irish Wheelchair Association

Advocating for equal rights for people with disabilities. Provides transport fleet, driving assessment and tuition, personal assistance and home care attendants.

Aras Cuchulain, Blackheath Drive, Clontarf, Dublin 3

Tel: 01 818 6400 Fax: 01 833 3873

Email: info@iwa.ie Web: www.iwa.ie

Mental Health Ireland

Promotes positive mental health and supports people with a mental illness, their families and carers.

Mensana House, 6 Adelaide Street, Dun Laoghaire, Co. Dublin

Tel: 01 284 1166 Fax: 01 284 1736

Email: info@mentalhealthireland.ie Web: www.mentalhealthireland.ie

National Association for Deaf People

Deaftech service provides advice and specialised equipment, including loop system.

35 North Fredrick Street, Dublin 1

Tel: 01 872 3800 Fax: 01 872 3816

Email: nad@iol.ie Web: www.nadp.ie

National Association for the Mentally Handicapped of Ireland (NAMHI)

National voluntary association working to improve the welfare of Irish people with an intellectual disability.

5 Fitzwilliam Place, Dublin 2

Tel: 01 676 6035 Fax: 01 676 0517

Email: info@namhi.ie Web: www.namhi.ie

National Council for the Blind in Ireland

Braille, tactile and computer aids, adaptive technology.

P.V.Doyle House, 45 Whitworth Road, Drumcondra, Dublin 9

Tel: 01 830 7033 Fax: 01 830 7787

Email: ncbi@iol.ie Web: www.ncbi.ie

National Federation of Voluntary Bodies

National umbrella organisation representing voluntary/non-statutory agencies providing services to people with intellectual disabilities.

Oranmore Business Park, Oranmore, Galway

Tel: 091 792 316 Fax: 091 792317

Email: fedvol@indigo.ie Web: www.fed-vol.com

People with Disabilities in Ireland Ltd

Representative structure through which people with disabilities can participate in and influence the decision making process on matters of concern to them.

Richmond Square, Morning Star Avenue, Dublin 7

Tel: 01 872 1744 Fax: 01 872 1771

Email: info@pwdi.ie

Vantastic

Provides door-to-door accessible transport services for people with disabilities in Dublin.

196 Howth Road, Killester, Dublin 3

Tel: 01 833 0014 Fax: 01 833 0663

Email: info@vantastic.ie Web: www.vantastic.ie

Groups Consulted on Participatory Research

Kerry Network of People with Disabilities

James Street, Tralee, Co. Kerry

Tel/Fax: 066 718 0611

Email: kerry@pwdi.org

Pathways

C/o Niamh Morrin, Canavan House, Nuns Island, Galway

Tel: 091 569 054

Email: louiemaquire@eircom.net

Making Minds Matter

Ulysses House, Unit 1B, 26-27 Portland Street North, Dublin 1

Tel: 01-865 8293

Appendix 3: Feedback Form

The NDA seeks to promote best practice in all its activities. We would appreciate if you, the user of these guidelines for including people with disabilities in research, would take some time to give us some feedback on your experience of using the guidelines by answering the questions below.

1. Could you briefly describe the situation in which you used these guidelines?

2. Did these guidelines meet your needs? How? Why?

3. What did you find most useful about the guidelines?

4. Do you have any suggestions for improving these guidelines?

5. Could you please provide the following information

Name _____ Organisation _____

Position _____ Date _____

THANK YOU. Please copy and return this form to:

Research Unit, NDA, 25 Clyde Road, Ballsbridge, Dublin 4

Tel/Minicom: 01 608 0400 Fax: 01 660 9935

Email: nda@nda.ie Web: www.nda.ie

The first part of the document discusses the importance of maintaining accurate records of all transactions. It emphasizes that every entry, no matter how small, should be recorded to ensure the integrity of the financial data. This includes not only sales and purchases but also expenses and income. The document provides a detailed list of items that should be tracked, such as inventory levels, customer orders, and supplier invoices. It also outlines the procedures for recording these transactions, including the use of standardized forms and the importance of double-checking entries for accuracy.

The second part of the document focuses on the analysis of the recorded data. It explains how to calculate key financial ratios and metrics, such as gross profit margin, net profit margin, and return on investment. The document provides step-by-step instructions for performing these calculations and includes examples to illustrate the process. It also discusses the significance of these metrics in evaluating the overall performance of the business and identifying areas for improvement.

The third part of the document addresses the issue of budgeting and financial forecasting. It explains how to develop a realistic budget based on historical data and market trends. The document provides a framework for setting financial goals and monitoring progress against these goals. It also discusses the importance of regular financial reviews and the need to adjust the budget as circumstances change. The document concludes with a summary of the key points and a call to action for the reader to implement the principles discussed throughout the document.